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Perspectives of peripartum people on opportunities for personal and collective action to reduce exposure to everyday chemicals: Focus groups to inform exposure report-back

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ABSTRACT

Participants in biomonitoring studies who receive personal exposure reports seek information to reduce exposures. Many chemical exposures are driven by systems-level policies rather than individual actions; therefore, change requires engagement in collective action. Participants' perceptions of collective action and use of report-back to support engagement remain unclear. We conducted virtual focus groups during summer 2020 in a diverse group of peripartum people from cohorts in the Environmental influences on Child Health Outcomes (ECHO) Program (N = 18). We assessed baseline exposure and collective action experience, and report-back preferences. Participants were motivated to protect the health of their families and communities despite significant time and cognitive burdens. They requested time-conscious tactics and accessible information to enable action to reduce individual and collective exposures. Participant input informed the design of digital report-back in the cohorts. This study highlights opportunities to shift responsibility from individuals to policymakers to reduce chemical exposures at the systems level.

1. Introduction

Since 1999, the Center for Disease Control and Prevention (CDC) has used biospecimens collected in the National Health and Nutrition Examination Survey (NHANES) to measure concentrations of environmental chemicals in the United States (U.S.) population (Centers for Disease Control and Prevention, 2009). Biomonitoring has also been

used in occupational and epidemiologic studies and more recently in community settings and patient populations (J. G. Brody et al., 2019). Increasingly, participants want to know their individual concentrations of chemicals and how they compare with others in their study, other populations, and "safety" benchmarks (Calafat et al., 2007; Centers for Disease Control and Prevention, 2021; Sjödin et al., 2018). In addition, when participants in chemical exposure biomonitoring studies receive

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personal reports on their own exposures, they consistently wish to learn how to reduce those exposures, and this information is a recommended component of personal report-back (J. G. Brody et al., 2014). For some types of exposures, tips for individual behavior change meet this need. However, many chemical exposures are driven by community-level, state, or national policies, regulations, and practices (J. G. Brody et al., 2019). For example, U.S. Food and Drug Administration (FDA) regulations do not require many consumer product labels to fully disclose all ingredients. Cosmetics labels, for instance, are not required to list the chemical constituents of added fragrances (Dodson et al., 2012a,b; Fair Packaging and Labeling Act, 1976; U.S. Food and Drug Administration, 2020). Further, most consumer products do not require any ingredient disclosure at all, so consumers have no way of knowing what chemicals are in their clothing, children's toys, or cookware. In such cases, regulatory- and policy-level change is necessary to facilitate awareness and avoidance of exposures. In some report-back contexts, participants have joined local organizations, participated in public hearings, or approached officials to seek systems-level change (Brown et al., 2012). Other participants have expressed frustration and uncertainty regarding the steps required to take action (Altman et al., 2008; Perovich et al., 2018). Yet little is known about participants' perceptions of their options for collective action, including use of report-back to support these efforts.

To fill this gap, this paper presents results from virtual focus groups that were held to inform the design of digital report-back of chemical exposures during pregnancy in two children's environmental health cohorts within the National Institutes of Health (NIH) Environmental influence on Child Health Outcomes (ECHO) Program (National Institutes of Health, 2021). Our focus groups discussed participants' knowledge of chemical exposures and their experience with and willingness to engage in personal and collective actions to reduce exposures in their homes and communities. This work is relevant to guide efforts to better address growing public concerns about the health effects of ubiquitous chemical exposures from consumer products, drinking water, food, environmental media (*i.e.*, air, water, and land), and other sources.

1.1. Ethical and theoretical frameworks for report-back in biomonitoring studies

Prior work has guided approaches to addressing the ethics, design, and logistical applications of participant report-back in chemical biomonitoring studies (Adams et al., 2011; Boronow et al., 2017; J. Brody et al., 2021; J. G. Brody et al., 2014; Ohayon et al., 2017; Ramirez-Andreotta et al., 2016a, 2016b). We briefly review critical frameworks that shaped the themes covered in our focus groups. These include research right-to-know, environmental health literacy, and exposure experience.

1.1.1. Research right-to-know

Participants in biomonitoring studies almost always want to know their own results, even when health implications are unknown or unclear (Morello-Frosch et al., 2009). Increasingly, individual report-back is recognized as an ethical best practice, and scientific ethics statements and federal ethics guidance support the right-to-know (J. G. Brody et al., 2007; hhs.gov, 2016; National Academies of Sciences, Engineering, and Medicine et al., 2018). "Research right-to-know" (Brown et al., 2012) is an extension of researchers' ethical obligation for individual report-back that incorporates principles of community-based participatory research (CBPR). The concept of research right-to-know maintains that research participants have the right to know the results of research conducted on them, notably in ways that support autonomy and action (Brown et al., 2012; Morello-Frosch et al., 2015). Engaging study participants in developing effective tools for report-back supports research right-to-know, in line with core CBPR goals of partnership, empowerment, and co-learning (Minkler and Wallerstein, 2011; Morello-Frosch et al., 2009; Springer Mellanie and Skolarus Lesli, 2019).

Research demonstrates that personal report-back generally does not

unduly increase psychological stress among participants (J. G. Brody et al., 2014) and can motivate them to consider both personal and collective strategies to reduce environmental chemical exposures (Adams et al., 2011; Altman et al., 2008). In addition, returning personalized biomonitoring reports can strengthen the "rigor, relevance, and reach" of future research studies by engaging participants in the scientific enterprise in concrete ways that are relevant to them, their families, and communities (Balazs and Morello-Frosch, 2013). Moreover, returning personalized biomonitoring reports can lead to new discoveries for researchers, encourage recruitment and retention in studies, and increase understanding of environmental health (J. G. Brody et al., 2014).

1.1.2. Environmental health literacy

Environmental health literacy (EHL) is defined as "an emerging and evolving multidisciplinary field that seeks to better understand how individuals and communities make sense of and act on health-related information about environmental hazards" (Hoover, 2019). EHL involves the ability of individuals to make informed personal decisions about environmental exposures and their ability to engage in community and public policy discourse regarding environmental health (Finn & O'Fallon, 2017). As action is a crucial piece of the framework, EHL involves skills and competencies beyond understanding environmental health information, including strategic assessment of the feasibility, likely impact, and uncertainties inherent in potential solutions to protect environmental health, and it requires that people have confidence in their ability to successfully carry out a plan of action (Hoover, 2019). Increasingly, rather than a unidirectional model centered primarily on knowledge acquisition, EHL encompasses an action-based framework that provides tools for individuals and communities to understand risks and control exposures (Ramirez-Andreotta et al., 2016b). The growing number of researchers doing report-back use presentations and tools that provide extensive information on sources and effects of contaminants, providing additional opportunities for EHL. Report-back of biomonitoring results can be an effective way to cultivate EHL. For instance, receiving personal results on chemicals found in household dust can change recipients' mental model of exposure, shifting conceptualization from faraway sources, such as waste dumps, to more intimate sources, such as indoor air and consumer products (Altman et al., 2008; J. G. Brody et al., 2019). EHL emphasizes interpretation of information about exposures within the context of the needs and values of a given community and with the goal of improving environmental health (Finn & O'Fallon, 2017; Hoover, 2019). Participant input into the development of report-back centers community priorities, providing an opportunity to increase EHL with culturally competent communication.

1.1.3. Exposure experience

Exposure experience, a subset of illness experience, is the ongoing process of identifying, understanding, and responding to chemical contamination (Altman et al., 2008). Exposure experience addresses the personal and emotional impact of chemical exposure. It is most often considered in the context of receiving chemical biomonitoring and household exposure (e.g., air, dust and drinking water monitoring) results; however, exposure experience is also a useful framework for investigating study participants' baseline perspectives, knowledge, and experiences related to exposure to environmental chemicals through everyday consumer products, personal care products, or environmental sources. This information can inform the development of personal exposure results return protocols for different study populations in ways that are understandable, meaningful, and actionable.

In summary, the frameworks of research right-to-know, EHL, and exposure experience support the ethics and benefits of report-back in biomonitoring both for participants and researchers alike. By extension, participant input into the development of report-back tools can enhance understanding of participants' baseline EHL and their preferences for how best to deliver biomonitoring results. Notably, a key component of EHL is the ability to act on knowledge to protect health. To position

participants to act, individual reports must provide context for participants to understand the meaning of their results and the steps they can take to reduce exposures. Information about such actions is a consistent, high-priority request from study participants. On the other hand, some participants who are motivated to join biomonitoring studies have less interest in their individual results and may be less willing or able to change personal behaviors. Understanding the reasoning and motives of participants who are highly interested and those of participants who are less interested in learning and acting individually on their report-back results is useful for advancing CBPR by offering insight into the range of participant perspectives. Furthermore, in reality, many exposures

cannot be reduced solely through individual action, such as informed consumption or reading product labels, due to the ubiquity of chemicals in many products and diverse pathways of exposure and due to the fact that industry is not required to fully divulge the ingredients and inputs of their products (J. G. Brody et al., 2019; Dodson, Nishioka, et al., 2012; Dodson, Perovich, et al., 2012). Thus, effective exposure reduction strategies often require policy and regulatory reforms or other community-level interventions. Crafting effective report-back involves determining which actions can be taken at an individual level and those that require a collective effort (J. G. Brody et al., 2019). Input from participants is crucial to effectively meet the need for guidance on

The image displays two screenshots of the 'My CIOB/ECHO Report' app interface. The top screenshot shows the 'Welcome to My CIOB/ECHO Report' page, which includes a header with the app name and 'Español' language option, a photo of a family, and a list of four bullet points: 'View your CIOB/ECHO study results', 'Learn about the chemicals in the study', 'Reduce chemicals in your home and community', and 'Learn about overall study results'. A red 'Get started' button is at the bottom. The bottom screenshot shows the 'Community Action' page, featuring a header with the app name and 'Español' language option, a photo of a woman speaking into a microphone, and text explaining that laws and community policies can protect everyone from harmful chemicals. It lists two bullet points about California's 2014 law on furniture flame retardants and San Francisco's 2018 law on PFAS in food service ware. Below this, it asks 'Your voice is important! Will you commit to taking at least one of these actions to keep toxic chemicals out of homes, schools, and workplaces?' and lists four action items: 'Make sure you are registered to vote', 'Join an environmental advocacy group', 'Ask your favorite brands and stores to choose safer chemicals', and 'Tell family, friends, coworkers, and neighbors something you learned about chemical exposures and health!'. A navigation bar at the bottom of the second screenshot contains a back arrow, a question mark icon, and a forward arrow.

Fig. 1. The Welcome page, Community Action page, and exposure reduction tips from the PFAS page of the My CIOB/ECHO Report. The smartphone-optimized report was built using the Digital Exposure Report-Back Interface (DERBI). Image used with permission. CIOB, Chemicals in Our Bodies; ECHO, Environmental influences on Child Health Outcomes; PFAS, per- and polyfluoroalkyl substances.

actionable community and civic engagement.

1.2. Digital exposure report-back interface (DERBI)

Digital tools are emerging to address barriers to high-quality report-back, such as researchers' lack of time, funding, and multi-disciplinary expertise required to build and deliver results. These tools are drawn from exposure science, epidemiology, health communications, and other fields (J. G. Brody et al., 2019; Ohayon et al., 2017). The Digital Exposure Report-Back Interface (DERBI) is a tested software framework for efficiently producing reports for print, computer/tablet, or smartphone. DERBI addresses the need for a nimble and scalable tool to deliver individually tailored reports that focus on the most relevant information for participants and the need to ensure interpretable results even in the absence of clear health guidelines or regulatory benchmarks (Boronow et al., 2017). DERBI can be adapted for different study populations, languages, and chemicals, and continues to evolve with feedback from participants (Boronow et al., 2017; J. Brody et al., 2021; Puerto Rico Testsite for Exploring Contamination Threats (PROTECT), n.d.).

DERBI is being used to report back prenatal environmental chemical exposures to participants from two pregnancy cohorts participating in ECHO (Fig. 1). Peripartum participants represent a unique study population for several reasons. The peripartum period entails rapid change related to the arrival of a baby, including changes in behavior at the individual and family level, new concerns and considerations related to child health and development, and changes in consumer habits (Goossens et al., 2018). Even as they are faced with competing demands on their time, energy, and resources in the setting of new childcare and family responsibilities, peripartum people are often highly motivated to avoid chemical exposures and protect their health and that of their children. This study provided an opportunity to investigate the baseline exposure experiences of participants who endured rapid lifestyle changes that made them uniquely attuned to environmental chemical exposures and who faced challenges in reducing those exposures. Therefore, we sought to learn from our participants how best to provide constructive information to reduce exposures at the individual and collective level.

2. Materials and methods

Through online focus groups, we sought to inform the development of biomonitoring report-back content for peripartum participants enrolled in two integrated and ongoing prospective pregnancy cohorts. "Peripartum" refers to the period from several weeks prior to giving birth to several weeks after delivery. "Peripartum people" refers to those in the peripartum period and is inclusive of people with diverse sexual and gender identities (Society for Maternal-Fetal Medicine et al., 2021). Our focus groups explored participants' knowledge of chemical exposures, making individual behavioral changes, and taking action at a community level to protect their own or their family's health and well-being and/or reduce their exposures to environmental chemicals. The focus groups further investigated the types of actions that were considered accessible and doable, and the variation that existed in those dimensions.

Focus group participants were recruited from the ECHO. CA.IL cohort, a combination of two ongoing longitudinal pregnancy and child cohorts: Chemicals in Our Bodies (CIOB) and Illinois Kids Development Study (IKIDS). ECHO. CA.IL was created as part of the NIH ECHO Program, which combines 69 cohorts, including 58 pregnancy cohorts, to address *in utero* and early life exposures and implications for child health outcomes, including perinatal outcomes, neurodevelopment, asthma, and obesity (Gillman and Blaisdell, 2018). These cohorts include biospecimen collection and measurement of environmental chemicals for examination in relation to child health outcomes (Buckley et al., 2020). ECHO. CA.IL is a geographically, socio-economically, racially and

ethnically diverse cohort that aims to evaluate the relationship between prenatal exposure to endocrine disrupting chemicals, prenatal stress, and measures of adverse birth outcomes and cognitive development of offspring in infancy and early childhood (Eick et al., 2021a,b). As of 2020, over 1387 peripartum people had been enrolled in ECHO. CA.IL (n = 822 in CIOB and n = 565 in IKIDS) (Eick et al., 2021).

CIOB is a prospective pregnancy cohort designed to examine the cumulative effects of environmental chemicals [per- and polyfluoroalkyl substances (PFAS) and polybrominated diphenyl ethers (PBDEs)] and psychosocial stressors on fetal growth. Recruitment for CIOB began in 2014 and is ongoing. The study population is racially and ethnically diverse (38% non-Hispanic White, 34% Hispanic, 17% Asian/Pacific Islander, 6% Black) and 20% are monolingual Spanish speakers. Pregnant people are recruited during their second trimester from hospitals at the University of California San Francisco, and their children are followed into childhood for growth and developmental outcomes (Eick et al., 2021; Morello-Frosch et al., 2016).

IKIDS is a prospective pregnancy cohort designed to examine how environmental factors, such as stress and exposure to chemicals (phenolic compounds, phthalates, and more recently, PFAS) during pregnancy impact early neurocognitive development. Recruitment for IKIDS began in 2013 and is ongoing. The majority of the study population is non-Hispanic White (80%) with a high proportion of participants with graduate education attainment (45%). Pregnant people are recruited during their first prenatal appointment at prenatal clinics located in Champaign and Urbana, IL, and are enrolled at 10–14 weeks of gestation. Offspring are followed into childhood (Eick et al., 2021).

The Institutional Review Boards at the University of California, San Francisco (10–00861) and the University of Illinois, Urbana-Champaign (09498) approved this study, and all participants provided informed consent prior to participating.

We conducted three virtual focus groups in the summer of 2020 to understand participants' experiences with everyday environmental chemical exposures, their thoughts on ways people can lower their own and their family's exposures, and their preferences for report-back to improve the efficacy of report-back for the entire cohort.

We conducted two focus groups for CIOB participants: one in English (N = 7) and one in Spanish (N = 3). We held one focus group for IKIDS participants in English (N = 8). For English focus groups, we recruited participants using personalized emails sent in batches until we obtained at least 10 acceptances. Participants represent a convenience sample as we targeted those who engaged in the study more recently or previously expressed interest in further participation. For the CIOB focus group held in Spanish, we invited all participants who indicated Spanish as their preferred language. Focus group participants were socioeconomically and ethnically diverse. Education levels ranged from a completed high school degree to a graduate degree. Participants identified as either non-Hispanic White, Asian/Pacific Islander, or Hispanic (we refrained from reporting specific numbers given the small sample size to avoid identifiability).

Facilitator guides for the focus group moderators were developed to address gaps in knowledge based on previous research studies that conducted individual interviews (drafted by [deidentified for review] and revised and reviewed by [deidentified for review]). The moderator guides were developed in English and tailored to the two study sites. The text of research materials including the CIOB facilitator guide was translated to Spanish by an American Translators Association (ATA)-certified translator specializing in environmental health issues. Translations were further reviewed by several bilingual research study staff.

Focus groups lasted approximately 90 min and were conducted online using Zoom video conferencing software (Zoom Video Communications, San Jose, CA). All focus groups were held virtually due to the COVID-19 pandemic to comply with social distancing guidelines and to ensure participant safety. Focus group facilitators (deidentified for review) had extensive experience conducting focus groups. Facilitators encouraged participants to keep their video on if they were able to

enable meaningful interaction and to mute when not speaking to minimize interruptions. Video and sound were recorded, and dialogue was later transcribed. Audio recordings of the English focus groups were transcribed by research staff member (deidentified for review). The Spanish focus group audio recording was transcribed and then translated to English by the same highly experienced, ATA-certified Spanish-English interpreter who translated all the study materials.

Moderators asked participants to describe their reasons for joining the study (either CIOB or IKIDS) and their thoughts and feelings about everyday environmental chemical exposures, notably any concerns, specific chemicals of concern, and reasons for concern. They also inquired about knowledge of study-specific chemicals and health effects. They then asked about past participation in collective action, interest in future participation, and barriers to participation. Focus groups ended with case scenarios regarding actions participants would take in the setting of hypothetical exposures, a poll assessing how likely participants would be to take specific actions to reduce exposures in their everyday lives, and feedback on “Toxic Matters,” a brochure on preventing environmental chemical exposures (McCarthy, 2016). Tips in the brochure are focused on five key areas: prevent exposure at home, prevent exposure at work, prevent exposure in your community, become a smart consumer, and make the government work for you (i.e., engage in collective action). These brochures are distributed by the Program for Reproductive Health and the Environment (University of California, San Francisco) to all study participants and at local health fairs. Each attendee received a \$50 electronic gift card for participation.

Focus group transcripts were coded and analyzed using Dedoose, a qualitative data analysis software platform. Codes were generated based on specific questions from the facilitator guide and broader conceptual themes addressed by the study drawn from the literature on social responses to environmental exposures and toxic discovery. Two authors (deidentified for review) independently excerpted text from focus group transcripts and assigned codes to recurring themes. Excerpts and codes were validated via independent excerpting and coding and subsequent comparison and reconciliation of discrepancies through discussion by the same two authors. Coding was further reviewed by research group members (initials deidentified for review) with extensive experience in codebook development and code assignment for additional verification and specification of patterns and themes. The facilitator guide, interview questions, and codebook are available from the researchers upon request.

3. Results

The results are presented according to the themes that emerged from a qualitative analysis of the focus groups. Broadly, these themes encompass participant motivation to participate in and learn from environmental health research, concern about environmental chemical exposures, and individual and collective action taken to reduce exposures, including associated challenges and potential solutions.

3.1. Motivation to participate in and learn from environmental health research

Across all focus groups, participants were curious about their chemical exposures and driven to protect the health of their families and communities in addition to their own health. They were motivated to contribute to research, promote policy change, and inform their friends, colleagues, and peers. One IKIDS participant commented on how research results can be used to inform policies affecting the wider community:

I like the idea of being able to contribute to science. But I also really love one thing I feel IKIDS touch[es] on a lot—the importance of changing policy. And so, I feel like that’s really cool to think about

my family, specifically, helping people make better laws that can protect all kids. That makes me super happy.

One Spanish-speaking CIOB participant further noted the benefit of expanding access to information by empowering others with information and promoting EHL:

I think that it’s a form of prevention, helping other people. Because not everybody else is in the study, not everybody else gets informed about the consequences of a toxic substance. So, giving them the information can help them with prevention, for the use of certain products both for themselves as well as for their children. In this case, it would be friends and family or people with young children so that they can make good decisions in the future.

Participants from the English-speaking CIOB group also cited helping peers and others as reasons for participating. One commented on both a desire to improve others’ experience of navigating toxics during pregnancy and the relevance of the study to her professional work:

I was really eager to participate and kind of use my experience of pregnancy to help other women have better experiences. I also have my Master’s in Public Health and studied environmental health and so this was really timely. I think I was just finishing my program when I got approached about this study, so I was really eager to participate. I’m glad I did.

Others likewise reported relevance to their professional fields in addition to curiosity and motivation to grow their own and others’ EHL. One IKIDS group member noted:

I’m a labor and delivery nurse, and I have a strong love for women and children’s health. And, when I found out about the study, it was a no-brainer to be able to participate and contribute and really just find out what chemicals are affecting us, and what we can do about it.

Relevance to professional work or field of study was more commonly cited as a motivating factor for participation among the IKIDS group (noted by 5 of 8 participants) compared with 1 of 7 CIOB English-speaking group members and 1 of 3 Spanish-speaking CIOB participants. While for most, such as those in healthcare, education, or public health fields, professional relevance did not involve concern regarding direct exposure to toxics. For one Spanish-speaking CIOB participant, the study was notably relevant to work-related exposure:

A reason that got my attention when I was told about the study was ... learning what chemicals are around and how I can [maybe] try to avoid them, especially for young children. And also, because I worked a lot at a nail salon. So, I wanted to know if that also affected or could affect my results in terms of chemical substances. I worked a lot with acetone, with nail polish and I was curious to know if that, in the future, could have consequences ... for my health.

3.2. Concern about environmental chemical exposures

Participants in all three focus groups had notable knowledge about the potential for chemicals in consumer products to affect health. They reported concern regarding specific environmental chemical exposures and their ubiquity. As one English-speaking CIOB participant put it: “The scary thing about all this is there are chemicals in everything everywhere.” In some cases, participants were unable to recall the chemical names or classes, but they were aware of the sources of chemicals in numerous consumer products. The most commonly cited sources of exposure were plastics, personal care products, baby products, cleaning products, and food packaging. In these groups of new parents, products used for babies, such as plastic pacifiers and toys, baby soaps, sunscreens, and other personal care products for children, were specifically mentioned apart from other sources. Regarding her own personal care

products, one CIOB participant stated:

There's something about putting things on my skin that felt like it was going directly to the baby. And food I guess too, but for some reason I was really obsessed with what belly oil I was using, or face cream, you know all that hair stuff, hair products. And I continue to be really aggressive on that.

People also mentioned furniture, kitchen tools (including utensils, cooking pans, and dishware), air pollution, paint, pesticides, lead, and BPA. Focus group participants were concerned about the detrimental effects of exposure to toxics on their pregnancies and children as well as themselves. Concerns regarding health effects ranged from general unease regarding "some disease in the future," per one CIOB Spanish-speaking group member, to more specific sequelae. For instance, one IKIDS participant reported particular concern for endocrine disruption, noting, "I've heard that there are endocrine disruptors, not only for yourself but also for your children. So that could affect their fertility and just, even how their bodies work long-term, and that kind of totally freaks me out."

3.3. Individual and collective action taken to reduce exposures

3.3.1. Individual action

Participants proactively took individual action to inform themselves and avoid exposures. They conducted personal research to identify and avoid chemical exposures, prioritizing actions that they believed would be most impactful at lowering their family's exposure. One English-speaking CIOB participant reported an increase in motivation to avoid exposures during pregnancy that persisted after the birth of her child; therefore, at the time of the focus group she was:

... looking up every little chemical and such, and then I also wound up moving into a new apartment and getting new furniture, so I was also doing research and making sure there wasn't the Prop 65 warning on all the furniture, trying to make sure it was safe because even that can produce chemicals.

As previously referenced, participants typically conducted their personal research on the internet, with some participants noting specific helpful resources, such as the Environmental Working Group's "Dirty Dozen" guide to pesticides in produce. Purchasing products perceived to reduce exposure burden was the most commonly reported individual strategy for minimizing exposures—for instance, buying plastic water bottles labeled BPA-free. Getting rid of old products, such as non-stick pans or couches "from the '80s", buying frozen rather than canned vegetables, and limiting the use of plastic, were additional examples of ways participants reduced exposure. As one CIOB participant reported:

... in my home my husband is really big on trying to get away from everything plastic. So, he got rid of all of our nonstick pans because those break down. Everything's metal, and he doesn't want me to use anything plastic, it's wood and metal.

3.3.2. Challenges to reducing exposures on an individual level

Participants expressed that on a personal level, ubiquitous exposures, uncertain health effects, a lack of robust and accurate sources of information, and competing priorities created challenges to identifying and prioritizing chemical exposures to avoid. One English-speaking CIOB participant expressed frustration with ubiquitous everyday exposures: "You don't know what to pay attention to or what's more serious. Or yeah, it's like, can I get a ranking of what to be most concerned about and pay attention to?" Similar sentiments were expressed across the focus groups, with one Spanish-speaking CIOB participant noting, "Sometimes you don't know what is good, what is bad. Or there are things that are good and, in the end, with time, they cause you damage." Participants also noted the implications of chemical substitution in

personal care products. As one IKIDS participant asked:

I look at them as paraben-free and then I wonder, 'Okay, so now they've replaced the paraben with something else. But, have we done enough research on whatever they have now replaced it with?' Is this gonna be something that 10 years from now, we're going to find out, 'Oh! This one was actually harmful to you as well?' Or have we done enough research on the new chemicals that they've put in instead of the paraben.

Participants discussed the mental and emotional toll of the many unknowns, particularly in the setting of a lack of accessible and trustworthy sources of information. An IKIDS participant commented on the emotional burden of making decisions in the face of pervasive exposures:

It's exhausting. I mean, everything is problematic and I have to really pick my battles carefully. I have a lot going on in my life, and I do the best I can for my family, but I cannot get all worked up about every little thing because it's just—it will never stop. And that's a spiral that I'm just not gonna give into.

Regarding a lack of reliable sources of information, an IKIDS participant reported:

I feel like there's not one trusted source that I know of to go to give me a list of products. And in the meantime, there's all these mommy bloggers filtering in, telling me to put essential oils on my kid so they don't have to wear sunscreen. And, I know that's not right. I don't want to listen to the mommy blogger. I want to listen to the scientist, but I feel like it's just that I haven't found that perfect source yet ...

Participants also juggled competing priorities. For instance, regarding the lack of options for a flame retardant-free car seat, a non-optional item to protect her child, one Spanish-speaking CIOB participant pointed out:

... the infant car seat, you buy it for the baby's protection, but on the other hand, it can also hurt him. So, it's something complicated because, on the one hand, it benefits you, but also, on the other hand, it's harming or can harm your baby.

People also faced financial constraints. As a CIOB participant mused, "Some things are more expensive if they don't have the chemicals in them, you know, and is it worth it?"

Others reported concerns about the judgments of others and disrupting needed service relationships, specifically with childcare providers. For instance, when asked about their thoughts on asking a place where their child spends the day to avoid flame retardants, one English-speaking CIOB participant explained:

There aren't that many preschools, and they're really hard to get into. So, I don't feel like I have the freedom to say 'if you don't listen to me, I'm just going to take my kids somewhere else.' It's like I want everyone to be happy, and harmony, and not see how the sausage is made. Like, it's fine, everything's fine.

The COVID-19 pandemic compounded everyday challenges by disrupting work, childcare, and school structures and adding stress and uncertainty to participants' lives. Many participants reported that COVID-19 added a layer of complexity to their reasoning around reducing environmental chemical exposures. Many stated that they were using more cleaning products during the pandemic in an effort to avoid infection. An IKIDS participant exclaimed, "We are so worried about trying to prevent viruses, I think about all the chemicals now we're putting on our hands, on our bodies, in our clothes!" Others commented on how COVID-19 disruptions limited the time and mental bandwidth available to devote to avoiding toxics. Another IKIDS participant reported:

I think it comes down to convenience also ... last week was 100 days for me working at home. And I don't have the time to run into town to get my kid after daycare, and come home and—my kid had macaroni and cheese last night, too, so you know, [laughter] yeah, otherwise, sometimes she doesn't eat [healthy, home-prepared food] because I have no other choice. And I'm not taking her into a store to go with me, you know? I'm doing the most convenient thing, and I know it's not right. I've been ordering some ... cleaner cleaning products, that come ... from a plastic-neutral company ... but still, things are coming in plastic ... it's convenience, currently, for me and I don't have the time to really care about something besides feeding and doing what I need to do to make sure we get through the day. Making all of the decisions, every day. Tons of decisions.

3.3.3. Solutions to enable individual action

Due to considerable uncertainty and time constraints, participants requested straightforward, specific, pragmatic recommendations for individual action to reduce exposures. Regarding time constraints, an English-speaking CIOB participant noted, "Something quick and easy is good, especially when I have three kids running around and [I'm] working full-time, it's very challenging to have some time." Specific recommendations were noted to be all the more necessary in light of COVID-19, both considering time and resource burdens imposed by the pandemic and additional pandemic-specific exposures, such as more cleaning products. Per one IKIDS participant:

What I need to know is – is this Clorox® spray that I have to spray to keep this pandemic out of my house going to be a problem? Because there's aerosol – I don't know what the right word is, air is expelling – and then there's also chemicals. So, it seems like there's two things that are a problem. And I just I don't know the science. I cannot discern what to do with any of this. I'm not a chemical engineer and I don't speak that language, but I need someone ... just tell me what to buy and I will buy it.

Another English-speaking CIOB participant expressed a desire for a clear, unambiguous list to guide purchasing of baby products: "The Environmental Working Group has the top ten, you know, the Dirty Dozen, the food groups that you should definitely buy organic. There should be that for baby-related products." Enabling ease of access to trustworthy and specific information was also cited as a key tool for expanding others' EHL and increasing participants' confidence in addressing toxics with others, such as childcare providers. Regarding asking a center where their child spends the day to avoid flame retardants, a CIOB participant commented:

... I'm really passionate about this, but I didn't ask about it [not using flame retardants at child's daycare]. And maybe it's ... knowing that it's a concern, but maybe not knowing how severe of a concern it is, or just not willing to rock the boat, once you're finally in somewhere. But if I had really specific talking points or data points I could share that I felt like I knew well enough to be able to convince someone to change then I would definitely feel comfortable doing that.

3.3.4. Collective action

Participants expressed a range of past experience in collective action. While 67% of participants did not report prior involvement in collective action, some participants had substantial relevant professional experience. Overall, 25% of IKIDS group members reported extensive experience, one with an asthma advocacy group, who went before their City Council to advocate for policies to reduce exposure to tobacco smoke, and another with the Illinois Environmental Council (IEC). The IKIDS participant with extensive prior involvement in political action through the IEC stated, "I follow, and am involved with, the Illinois Environmental Council, which is a state-wide lobbying group for environmental issues in Springfield. I do a really good job talking about the legislative

issues in Illinois, around environmental topics and concerns ..."

Of English-speaking CIOB participants, 57% reported past experience in collective action. Two group members noted professional ties influencing action, one who previously worked on political campaigns and as a political consultant and one with years of experience as a social worker. Overall, 33% of Spanish-speaking CIOB attendees reported prior involvement. Regarding their history of taking collective action on chemicals or other issues of importance to them, a Spanish-speaking CIOB participant discussed supporting equity in education:

I was in a group of people that were trying to get the school district to pay more attention to children of color, well, of different races. And it was like community meetings where ideas were brought up and their representatives went and talked with legislators so that they would be at the same academic level as the rest of the children here in San Francisco.

3.3.5. Challenges to reducing exposures at the level of collective action

In considering their willingness to engage in collective action on environmental health, people commonly cited limited time and competing priorities as barriers to more extensive involvement, though the experience in the focus group revitalized participants' motivation to engage. One English-speaking CIOB participant with a strong history of volunteering for various causes also acknowledged the reality of competing priorities:

I've definitely volunteered over the last 15 years for many different organizations. What I struggle with is just, I'm a single mom and just, time. And so that's where I haven't gotten as involved, just between work and that, where I've allowed myself to really commit deeply to one thing that I can really get involved. And instead, I do the "great, I have two hours, I can go do this thing that doesn't require an ongoing commitment." But I would like to do more.

Another English-speaking CIOB participant with more limited prior engagement in collective action added:

I haven't joined in the [environmental advocacy] group because I'm a full-time mom. It's like what you said—time is precious. Sometimes 24 h is—I need more time with my kids, with the household. I wish maybe when my kids are grown up, I can join an organization, which I want to.

As with individual action, the COVID-19 pandemic impacted collective action by disrupting work and childcare routines and adding stress and uncertainty, further limiting time and resources available to devote to avoiding toxics. As one English-speaking CIOB participant explained, "In the last 4 months, it's been ... like, 'Eh, let's get through this pandemic and then we'll figure out how to make that [taking action to reduce exposures] a priority again.'"

3.3.6. Solutions to enable collective action

Across all groups, participants acknowledged the benefits of collective action to reduce exposures when they had less control over the exposures in their environment, and the participants reported a desire for greater involvement at the community level. Due to considerable uncertainty and time constraints, participants requested straightforward, specific recommendations to guide action. One IKIDS participant commented, "If there was a group, and you gave us information on exactly what to ask, or to say to legislators, I would." Another IKIDS group member, voicing her thoughts on contacting a lawmaker to advocate for labeling of products containing phenols, asserted, "... it would help to have prompts, and have that consistent messaging ... reminding me that I care about this, and that I'm not the only one who's dealing with these issues." She further acknowledged the limitations of individual action and remarked that it would be helpful to have salient messaging to counteract frameworks that place the burden of action on individuals:

... collectively, I think we have an opportunity to make a difference such that we don't have to keep having these shameful discussions of, 'Oh, I feel like a bad mom because I have to feed my kids, and I don't have room in my day to actively research every single product that we're interacting with.' That is, I think, a specific type of messaging we've been indoctrinated with to keep us overwhelmed and feeling like we can't change anything.

Others discussed the utility of platforms to expand others' EHL, such as peer groups. In response to what they thought they could do with others to lower exposure to flame retardants in the community, one English-speaking CIOB participant stated:

... just bringing more awareness to that [flame retardant exposure in the community] – if we missed it, it's something that probably the broader community is not aware of. And so how to do that? I think at least in San Francisco, there's moms' groups, etc. Leveraging those maybe as a start.

Regarding specific actions they would take, participants considered signing a petition to support actions to reduce the use of harmful chemicals to be most doable; almost all participants indicated that they "would" or "definitely would" sign such a petition. Most IKIDS participants also reported openness to calling an elected representative to ask them to support new laws about chemicals in consumer products, and about half of CIOB participants indicated that they "would" or "definitely would" call an elected representative.

4. Discussion

These focus groups provide insight into the baseline (that is, prior to receipt of chemical biomonitoring results) exposure experience of a geographically diverse group of peripartum people and shed light on the information and resources participants need to advance their EHL. They provide insight into the barriers and strategies for engaging in individual and collective action, and they establish a foundation for building recommendations about individual and collective action opportunities into report-back.

The National Academies of Sciences, Engineering, and Medicine 2018 *Consensus Report on Returning Individual Research Results to Participants* encourages researchers and institutional review boards to routinely consider report-back "as a matter of reciprocity, respect, transparency, and trust" (National Academies of Sciences, Engineering, and Medicine et al., 2018). Individual report-back of biomonitoring results has the potential to yield a variety of positive results strengthened by the inclusion of recommendations for action (J. G. Brody et al., 2014; National Academies of Sciences, Engineering, and Medicine et al., 2018). Report-back may provide information of personal value to participants to inform decision-making about health and quality of life and can promote public engagement and trust in the research process as well as engagement in regulatory and policy development (J. G. Brody et al., 2014; Morello-Frosch et al., 2009; National Academies of Sciences, Engineering, and Medicine et al., 2018). Furthermore, report-back may support recruitment and retention of research participants (D. Kaufman et al., 2008; D. J. Kaufman et al., 2016; Murphy et al., 2008). By centering participant perspectives, focus groups help tailor report-back content to community and cultural contexts and can foster transparency and trust between researchers and community members. Furthermore, by working with participants to ensure that exposure reduction strategies are accessible and relevant to the community, report-back is more likely to be translated into measurable impact on people's chemical exposure. Crucially, focus groups allow research participants to shape report-back and enable growth of EHL by aligning report-back tools with participant goals, thereby positioning participants to act on their knowledge in line with the concept of research right-to-know.

CIOB and IKIDS focus group participants emphasized several key

areas to enhance their knowledge and better position them to act. Participants desired greater involvement in reducing exposure to toxics but faced limited time and resources. The COVID-19 pandemic compounded existing stresses and added new ones, which impacted the actions participants were willing and able to take. In the realm of individual action, they repeatedly requested straightforward, easily accessible information, particularly with respect to product recommendations. As part of report-back, researchers should share evidence-based tips for reducing individual exposures. For example, DERBI offers tips, such as "Choose fresh or frozen instead of canned food or drinks" to reduce exposures to bisphenols, or "Avoid spray treatments that make rugs, furniture, shoes, or other textiles stain- or water-resistant" to limit exposure to PFAS (Fig. 1). In some cases, providing detailed product recommendations is challenging for individuals and researchers alike given the vast number of chemicals in commercial products, limited labeling requirements in the U.S., and frequently changing product formulations.

A different approach is for researchers to highlight the role of collective action in shifting the burden from individuals to regulatory agencies. For example, stronger ingredient disclosure laws would facilitate access to information about chemicals in products, and requirements for safety testing would prevent harmful chemicals from being used in products from the start. Researchers can provide examples of cases in which collective action brought about policy change and suggest ways for participants to engage in collective action. Similar to individual action, participants also desired time-conscious tactics and robust, accessible information to engage in collective action. Researchers can help meet these needs by facilitating connections to ongoing collective action efforts in their communities. For instance, in the Northern California Household Exposure Study, the research partner Communities for a Better Environment was involved in data collection and report-back, contacted participants, and provided public forums for participant involvement, such as through testifying at hearings on oil refinery expansion (Brown et al., 2012). Such partnerships can mutually benefit participants and community-based organizations, linking participants to resources grounded in their communities and enhancing community-based organization's staff understanding of research methods and interpretation (Brown et al., 2012). In cohorts that are not place-based, researchers can direct participants to nationally based advocacy organizations and encourage behaviors, such as voting and contacting manufacturers, businesses, and legislators. Examples of tips for collective action in DERBI include "Make sure you are registered to vote and elect candidates who support more protective laws on toxic chemicals" and "Ask your favorite brands and stores to choose safer chemicals. Join campaigns to get chemicals of concern out of food packaging and consumer products." As several focus group participants also noted, simply spreading the word and sharing knowledge about chemical exposures with others is a valuable form of engagement.

The focus groups also provide insight into the particular exposure experience of the peripartum population. The new parents involved in the groups reflected on the unease of toxic discovery during pregnancy and parenthood, such as highlighted by the CIOB participant who remarked, "There's something about putting things on my skin that felt like it was going directly to the baby." The peripartum period emerged as a time of heightened burdens and responsibilities but also as a time of increasing awareness and perceived urgency of action. While participants acknowledged the time, energy, and other resources needed for family and childcare responsibilities, they were also highly interested in environmental health and were motivated to protect themselves and their babies. Participants looked to the future and to their communities as parenthood drew attention to the impact of exposures beyond themselves.

Input from CIOB and IKIDS focus groups was used to inform the digital exposure report-back interface, DERBI, by adding resources on opportunities for local and national collective action on the platform. My CIOB/ECHO Report (Fig. 1), which includes PBDE and PFAS results, highlights California's success in changing the flammability standard

and action by the City of San Francisco to ban PFAS in single-use food service ware. The report calls on participants to “Ask your state representative to follow San Francisco’s lead and ban PFAS in single-use food service ware, like take-out containers, in all California.” In My IKIDS Report, which includes results for environmental phenols, attention is drawn to the U.S. Food and Drug Administration (FDA) ban on triclosan and decreasing levels of triclosan in the study population. In both reports, participants are encouraged to join environmental advocacy groups, and weblinks are provided for local and/or national advocacy groups that are tailored to each study (Fig. 1). The focus groups also informed pre- and post-surveys conducted before and after participants viewed their chemical results in the two cohorts. These surveys aim to test the ability of DERBI to grow EHL, change behavior to reduce exposures, and encourage steps toward collective action. These surveys are administered before and after participants receive their individual chemical results from the study.

One potential limitation of these focus groups is whether the group participants are representative of the broader CIOB and IKIDS cohorts and ECHO participants, and the wider peripartum population outside of the ECHO Program. English-speaking focus group participants represent a convenience sample as we targeted those who engaged in the study more recently or previously expressed interest in further participation. As a result of this recruitment strategy, participants may reflect a higher level of engagement than in the broader cohorts. For example, all focus group participants expressed interest in taking some form of action to reduce exposure, even if they had little time to invest. These focus groups cannot provide insight into those participants who do not have any interest in lowering exposure or engaging with their personal results. Similarly, participants may demonstrate greater knowledge of the potential for chemicals in consumer products to affect health than the general population. For the CIOB focus group held in Spanish, we invited all participants who indicated Spanish as their preferred language. The recruitment of Spanish-speaking participants can present challenges, such as language discordance and potential cultural differences between participants with Spanish as their preferred language and the majority of research staff (Bonevski et al., 2014; Halcomb et al., 2007). Accordingly, we used strategies, including tailored and engaging recruitment materials, the involvement of bilingual study staff, and a certified interpreter for recruitment and engagement among Spanish-speaking participants (Rhodes et al., 2018). Across all focus groups, the relatively small number of participants and the ways in which participants may differ from those who did not participate may limit the generalizability of our findings. Despite these limitations, our focus groups incorporated participants from two geographically distinct and demographically diverse areas and included two languages. Additional research is needed to further characterize perceptions of exposure experience and the role of collective action in reducing exposures in the peripartum population. Further research can provide an even greater impetus for large studies, such as the NIH’s All of Us Research Program, to adopt report-back methods similar to ours.

5. Conclusion

Researchers have the opportunity to learn from participants’ reported strengths, challenges, and desires to improve future report-back of chemical (or study) results. The peripartum population in our studies included a knowledgeable and motivated group of parents despite their significant time and emotional burdens. Tailored report-back information can support their motivation to individually and collectively reduce chemical exposures. According to the National Institute of Environmental Health Sciences (NIEHS) framework for translational research, researchers have a responsibility to translate research findings into impacts on individual behavior and policy (National Institute of Environmental Health Sciences, 2022). Given the limits of individual actions and the need for collective action, researchers must grapple with their role in shifting responsibility from

individuals to decision-makers to reduce chemical exposures to protect parents and children.

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Data availability statement

The datasets for this manuscript are not publicly available because, per the NIH-approved ECHO Data Sharing Policy, ECHO-wide data have not yet been made available to the public for review/analysis. Requests to access the datasets should be directed to the ECHO Data Analysis Center, ECHO-DAC@rti.org.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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